

Social Security Administration
Compassionate Allowance Outreach Hearing on Cancers
Monday, April 7, 2008

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Commissioner Asture, fellow panel members and guests:

I am honored to speak with you today on behalf of the American Cancer Society, the nation's largest voluntary non-profit health organization, and our millions of dedicated volunteers in communities across the country. As you know, the Society is committed to reducing the suffering and burden of cancer, so we applaud your willingness to have this hearing to discuss approaches to streamlining the disability process for those most in need.

We have been fortunate over the past 25 years to substantially reduce the risk of death from cancer through advances in prevention, early detection and treatment. There are now almost 11 million cancer survivors in the United States and countless lives have been improved by our nation's efforts to treat this deadly disease.

Despite our progress, unfortunately, there are still many who are diagnosed too late for effective treatment, or who have a form of cancer that is not responsive to many of the treatments we currently have available. For those individuals and their families, the words "you have cancer" carry an even greater burden.

For these people, the burden extends beyond the diagnosis and treatment of their cancer. There are serious financial concerns for many people faced with a diagnosis of cancer, including access to care, the costs of treatment, and the inevitable financial difficulties associated with daily living, including the loss of employment income. For many, what may have been routine expenses prior to their diagnoses suddenly and quickly can become almost insurmountable.

The American Cancer Society has made access to health care a top priority. We recognize that without access, our efforts to promote prevention, early detection and treatment can become meaningless if people can't afford to get the care they need. The problem is obviously a serious one for the nation's 47 million uninsured. But it is also a problem for millions of people who have health coverage but discover too late that it is inadequate—the cost of full treatment for their cancer is beyond their means because of high deductibles and co-pays, limits on benefits, or the lack of coverage of necessary services.

In 2001, an estimated 2 million Americans experienced bankruptcy caused by illness and medical bills. Approximately ten percent of these cases were caused by cancer-related costs. Cancer was the highest cost diagnosis with average out-of-pocket medical costs of \$35,878 compared to the next highest cost diagnosis, neurologic diseases, at \$15,560.

We know that 25% of cancer patients used up all or most of their savings during the course of their treatments. One in five of these individuals had health insurance. For many people, cancer presents an ever-increasing mountain of bills for themselves and their families.

We can only imagine the distress that many patients and their families experience when they discover that there is no safety net to catch them financially once they are diagnosed with cancer. Facing intensive treatment to save their lives, they may also have to cope with the fact that they are truly disabled and unable to perform their daily work-related activities. Their jobs disappear, their income and savings disappear, and for many, their short term outlook is dismal.

For some of these individuals and their families, we have the opportunity to address and correct what has become a burdensome and cumbersome system—the Social Security Disability Insurance program (SSDI). This program, if better structured, could provide a vital level of financial support in a time of great need.

Our purpose here today is to address how we might streamline and improve the process by which Social Security disability benefits are determined and initiated. We would also like to put on the table for discussion the question of the two year waiting period for Medicare for those who become disabled prior to their 65th birthday.

Many in this room today are all too familiar with the laws and rules and regulations surrounding Social Security Disability Income and Medicare programs for the disabled.

The five month waiting period for SSDI (which is in reality frequently substantially longer than that because of administrative backlogs) and the two year waiting period for Medicare benefits for those who are disabled are legendary to those of us in the cancer community who see first hand the devastating impact of these requirements.

The American Cancer Society is committed to eliminating the two-year waiting period for cancer patients to obtain Medicare coverage and eliminating other administrative hurdles that prevent timely and essential medical and financial support. Currently, individuals under age 65 with disabilities, including late stage cancers, can technically obtain Medicare coverage based on their disability. However, the two-year waiting period makes it extremely difficult for a cancer patient to obtain coverage. The two-year waiting period is particularly detrimental to those individuals with late stage cancer or more deadly cancers like pancreatic cancer where the probability of surviving two years is very low.

Aggravating the coverage delay is the fact that before an individual with late stage cancer can acquire SSDI or Medicare coverage, he or she must first receive a disability determination from the Social Security Administration (SSA), which can take months. Only then, after the determination from the SSA, does the two year wait to obtain Medicare coverage begin.

As I mentioned previously, the unfortunate reality is that for many patients diagnosed with cancer, their outlook is grim. The waiting periods are especially onerous for these patients under the age of 65 who present with certain cancer diagnoses and/or advanced disease, those for which the probability of survival is known to be low. These patients not infrequently go through their diagnoses and treatments without ever having been able to receive a final disability determination. Even within my own family, there have been circumstances where the time from diagnosis to death was measured in months, too short a period to get either disability coverage or Medicare benefits.

We do believe there are certain criteria which could be applied that would help accelerate the disability determination process and thereby provide a more reasonable approach to getting benefits to beneficiaries in need in a more expeditious manner.

When you review the data from the Surveillance Epidemiology and End Results database of the National Cancer Institute (commonly known as SEER), you can quickly find diagnoses that are associated with particularly onerous prognoses, where a majority or close to a majority of the patients diagnosed with particular cancers have a survival of less than one year. Examples include lung cancer, the most common cause of death from cancer for both men and women in the United States in 2008, where the majority of patients present with advanced disease. For patients under the age of 65 diagnosed with lung cancer, the one year survival is under 50%, or 46.9%.

For patients with acute myeloid leukemia under the age of 65, the one year survival is 52.7% for men and 59.3% for women.

For patients with localized esophageal cancer, the one year survival ranges from 38.7% for black men to 51.5% for white women.

Pancreatic cancer is particularly deadly. In 92% of patients, it is a disease that is usually diagnosed beyond the moment when it can be successfully resected. For all patients under age 64, the one year survival ranges from 21.7% for black men to 32.4% for white women.

I believe the point is clear: there is much more we can do to make certain that, at a time of the greatest need that any of us can imagine, we do not increase the burden of suffering for those with cancer and their families by continuing to impose inordinate approval and waiting periods to get benefits to those who all of us agree need them most.

We propose that Congress and the Social Security Administration work legislatively and through regulation to establish a process which, under certain defined circumstances, would eliminate the waiting periods to receive SSDI and Medicare benefits for patients with certain cancer diagnoses. These patients would meet redefined and more appropriate disability criteria which reflect their medical need and expected survival.

We could base these criteria on survival probabilities as determined by diagnosis, stage at presentation, and treatments. The criteria could be established through an expert panel

and public comment, and could serve at least as an initial “filter” to be certain that those in most need are moved to the head of the line for disability determination.

If we applied a rule of reason, I doubt there are any of us who could object to making certain that hard working people and their families, in their moment of greatest need, should have access to benefits they have worked for, paid for, and deserve. Faced with the diagnosis of a near term fatal illness, frequently anticipating debilitating and expensive medical care, or perhaps requiring end-of-life care, we could at least offer them some comfort in knowing that we cared enough to provide some of the help that they desperately need and deserve. And spare them the fear of significant debt.

Again, we appreciate having the opportunity to appear before you today and look forward to answering your questions. We look forward to working with you, Congress and the Administration to provide whatever help we can to address a need that is so obvious but has been ignored for so long.

Your willingness to provide a forum and focus for this topic is much appreciated.

Thank you.